#### **Frequently Asked Questions and Answers**

### "Cancer mortality in India: a nationally representative survey" Lancet, March 28, 2012

Disclaimers:

The aim is to give only information, not recommendations, to governments, organisations and individuals.

Note on Indian and western numbers: 1 lakh=100 thousand, 10 lakh=1 million, 1 crore=10 million

#### Q: What is the Million Death Study?

A: The Million Death Study (MDS) is large-scale, epidemiological research study intended to document the causes of child and adult deaths in India and their key risk factors for the years 1998 to 2014. The MDS works within the Sample Registration System (SRS), which is a large, ongoing demographic survey organized by the Registrar General of India (RGI). In this particular report, deaths due to cancer were analysed for the first phase of the MDS, from 2001 to 2003.

#### Q: Who carried out the study, how much did it cost and who funded it?

A: The SRS is funded and implemented by the RGI. The MDS is led by the Centre for Global Health Research (CGHR) at the Li Ka Shing Knowledge Institute, St. Michael's Hospital and University of Toronto, Canada. The study was conducted in close partnership with the Tata Memorial Hospital, RGI, St. John's Research Institute, the Post Graduate Institute of Medical Research and Education, the Indian Council of Medical Research, and the Clinical Trials Service Unit and Epidemiological Studies Unit at Oxford University. The MDS cost approximately \$1 million Canadian dollars (Rs. 4 crore) over a five year period and was primarily funded by the U.S. National Institutes of Health and the Canadian Institutes of Health Research. The funding agencies had no role whatsoever in writing the final scientific paper, as this was the responsibility of the investigators.

#### Q: How were data for this study obtained?

A: Using SRS data on all deaths that occurred during the 2001-2003 period, a team of approximately 800 trained, non-medical field staff obtained individual narratives (or "verbal autopsies") from household members about the circumstances surrounding the deaths in their homes during these years. Quality control methods, including random spot checks, were conducted routinely.

#### Q: How was cause of death determined?

A: Based on the local language of the narrative, each field report was randomly assigned to at least two of 130 physicians. Using the information provided in the verbal autopsies, the physicians independently coded the underlying causes of death using a 3-character International Classification of Diseases (ICD-10) code. Physicians were instructed to use their best medical judgment to determine the cause of death. Any differences between the two coders were resolved either through anonymous reconciliation or adjudication by a third physician.

#### Q: What are the key findings of this study?

A: Key findings:

- About 6% of all deaths in India are from cancer, and 70% of cancer deaths happen between the productive ages of 30-69 years
- There were an estimated 560 000 national cancer deaths in India in 2010
- The three most common causes of cancer death in males were oral, stomach, and lung cancer; in women, these were cervical, stomach and breast cancer
- Tobacco-related cancers were estimated to contribute almost 1.2 lakh deaths in 2010, and were responsible for over 40% of male, and nearly 20% of female cancers
- Cancer mortality rates were similar between rural and urban India
- The risk of dying from cancer was two times higher in the least educated than in the highest educated adults
- There are large variations in risk of cancer death across Indian states; the cancer death rate is highest in north-eastern states and Assam, while it is lowest in Odissa, Bihar and Jharkhand

# Q: How do the results from this study compare to the estimates made by the World Health Organization (WHO), or those projected by the Indian National Cancer Registry programme?

A: There are 24 cancer registries in India, however only two of them are in rural areas. As about 70% of Indians live in rural areas, estimates based on registry data may not be nationally representative. Furthermore, even in areas where cancer registries exist, the mortality information may be incomplete. However, the top causes of cancer mortality in India are comparable between the MDS and Indian registries.

The International Agency for Research on Cancer (part of WHO) estimated that there are around 633, 000 cancer death in India every year, similar to the estimates obtained in this study.

## Q: How can we tell that verbal autopsy is a valid way of obtaining information on cancer deaths?

A: A 5% resample of deaths within our survey, and previous independent studies conducted in Tamil Nadu and Chandigarh have determined that verbal autopsy is a valid tool for determining cause of death, including cancer. Further features within our study design also ensure high quality of data, including screening and cleaning of data, as well as requirement of independent agreement on cause of death by two physicians.

#### Q: Why do the results only include those deaths under the age of 70?

A: Deaths between the ages of 30-69 are most likely to be preventable from a public health point of view, and are thus the focus of our study. Furthermore, assigning cause of death in old age (70+) is particularly difficult, and the proportion of total deaths without a classifiable cause rises sharply after this age.

#### Q: Who participated in this study?

A: The Registrar General of India (RGI) funds and organises the Sample Registration System (SRS), which monitors all births and deaths in 1.1 million (11 lakh) homes covering all

geographic regions of India. Field workers interviewed 122 thousand (1.22 lakh) households located in 6671 areas (4436 rural and 2235 urban) that were chosen to be representative of the entire population of India.

#### Q: What are some of the limitations of this study?

A: Diagnosis of anatomically specific cancers is difficult within verbal autopsy. There may be some misclassification of cancer sites which are adjacent to each other, such as those within the abdomen and thorax, as well as those which have spread from an earlier cancer (i.e., liver, brain). However, misclassification is a smaller concern for cancers which are anatomically distinct (i.e., oral, breast, and cervical).

#### Q: Are these results outdated since the analysed data are from 2001-2003?

A: The proportions of death by cancer site are not likely to have changed greatly in the last decade, as such changes require a long time frame to occur, and because India has not introduced any significant cancer prevention strategies within this time. Likewise, our estimates of rates and numbers of cancer deaths for 2010 are based on these proportions, as well as the most recent UN population numbers.

This is the first phase of research findings from the Million Death Study (MDS) and data will continue to be collected until 2014.

#### Q: Why are cervical cancer mortality rates lower in Muslim than in Hindi women?

The precise reasons for differences in mortality rates among Hindu and Muslims will have to be investigated in a separate study designed to find the causes of cervical cancer. However, the higher prevalence of circumcision among Muslim men is known to reduce transmission of HPV, which is the virus that causes cervical cancer.

However, cervical cancer can be prevented in all adults, irrespective of religion, education or geographical region, by vaccination for HPV before marriage, and by proper screening and treatment.

#### Q: What do these results mean?

A: Cancer is an important cause of mortality in India, and equally affects both rural and urban areas. Cancer is also a significant burden in poor and uneducated, as illiterate adults had twice the risk of dying from cancer as the most educated ones. Large differences in cancer mortality rates between states, as well as large numbers of deaths from tobacco and infection-related cancers indicate that the majority of cancer deaths can be avoided.

#### Frequently Asked Questions about Cancer

#### Q: What is cancer?

A: Cancer is the name given to a large group of diseases, all of which have one thing in common: cells that are growing out of control. Normally, the cells that make up all of the parts of our bodies go through a predictable life cycle -- old cells die, and new cells arise to take their place. Occasionally, this process goes awry, and cells begin to multiply out of control. The end result is a mass of cells, called a tumour. A benign tumour is one that does not spread, or metastasize to other parts of the body. It is considered noncancerous. A malignant tumour, on the other hand, can spread throughout the body and is considered cancerous. When malignant cells break away from the primary tumour and settle into another part of the body, the resulting new tumour is called either a metastasis or a secondary tumour.

#### Q: What causes cancer?

A: There are many lifestyle and environmental risks factors associated with the development of cancer, such as obesity and excessive alcohol consumption. The risk factors for the most prominent cancers are smoking and chewing of tobacco (lung and oral cancers), infection with HPV (cervical cancer), and hepatitis B and C viruses (liver cancer).

#### Q: Is cancer curable?

A. Most cancers can be cured if they are detected at an early stage.

#### Q: What are the symptoms of cancer?

A: Since cancer can arise from such a wide variety of sites and develop with many differing patterns of spread, there are no definitive symptoms. The nature of cancer symptoms may also depend on the location of a tumour within an organ, rate of development, and whether metastasis has occurred.

Many primary tumours cause a local swelling or lump if they arise at a visible or accessible part of the body, such as a skin, breast, testicle or oral cavity. A typical swelling due to a cancer is initially painless, though ulceration (skin breakdown) can occur, which may then become painful.

#### Q: How is cancer diagnosed?

A: Personal signs and symptoms may provide suspicion of cancer, which can be confirmed by medical examination. For breast cancer specifically, breast self examination is the best way to detect a lump, while mammography after the age of 40, and clinical breast examination after age of 50 can help to detect breast cancer at an early stage.

#### Q: What are different treatment options for cancer?

A: Depending on the type of cancer, it can be treated by surgical removal of cancerous tissue, radiotherapy, and/or chemotherapy.